Lyme Disease Advisory Committee Minutes of the January 10, 2001, Meeting Department of Health Service, Sacramento

The second meeting of the Lyme Disease Advisory Committee (LDAC) was held on January 10, 2001, in Sacramento, California.

Committee members present:

Alan Barbour, M.D., University of California, Irvine
Jean Hubbard, Lyme Disease Resource Center
Vicki Kramer, Ph.D., California Department of Health Services
Robert Lane, Ph.D., University of California, Berkeley
Susie Merrill, Lyme Disease Support Network
Scott Morrow, M.D., California Conference of Local Health Officers
Christian Parlier, Lyme Disease Support Network
Raphael Stricker, M.D., California Medical Association

Committee member absent:

Lee Lull, Lyme Disease Support Network

Guests:

Lucia Hui, Department of Health Services Anne Kjemtrup, D.V.M., Ph.D., Department of Health Services Robert Murray, Ph.D., Department of Health Services Linda Sandoval, Department of Health Services

1. Introductions

Dr. Lane, Chair, called the meeting to order at 10:00 a.m. He asked that the Committee members and guests introduce themselves.

2. Review minutes of October 24, 2000

Dr. Lane reminded everyone that the minutes of the LDAC meetings are confidential until all of the members have approved them, and are not for distribution until the approval process has taken place. Dr. Lane asked if there were any comments regarding the minutes; there were none.

The minutes of the October 24, 2000, meeting had already been approved electronically (via email) on December 15, 2000. Dr. Lane asked for formal approval of the minutes. Mr. Parlier moved, seconded by Dr. Stricker, to approve the minutes of October 24, 2000, as written. The motion carried unanimously.

3. Review and finalize mission statement

Dr. Lane asked the Committee members to review the mission statement.

Discussion on the changes included comments on including the word "tick" in the statement, and mentioning other tick-borne diseases. Consensus of the Committee was to change the mission statement to read as follows:

The mission of the Lyme Disease Advisory Committee is to make recommendations to the California Department of Health Services on strategies to enhance the awareness of the public and the medical community about Lyme disease in California, and thereby reduce exposure to, and suffering from, this and other tick-borne diseases.

The Committee approved unanimously the mission statement as revised.

4. Brief review of goals established on October 24, 2000

Dr. Lane reminded the Committee that the goals suggested at the last meeting were organized into a grid and categorized under the following five headings:

- Educate Medical Community
- Educate General Public
- Educate School Children
- Risk Assessment
- Disease prevention

Dr. Lane stated that the objective of the present meeting was to evaluate the appropriateness of each goal in regard to the LDAC mission statement. If a goal was not concrete or appropriate as written, attempts would be made to rewrite the goal so that the concept could be achieved.

5. DHS progress report (Anne Kjemtrup)

As a first step towards addressing the goals established at the first meeting, Dr. Kjemtrup gave an update on the work accomplished to date.

Under the education-related categories, Dr. Kjemtrup reported that she had made several attempts to submit articles on Lyme disease in California to various journals specific to physicians in California.

The California Medical Association (CMA) quarterly journal, <u>California Physician</u>, would only accept a very brief paragraph on Lyme disease in California, and this under a section entitled "Have you heard...anecdotes, newsbites and absurdities." This required format was deemed inappropriate for publication of an important message.

Dr. Lane gave an update on his work on attempting to submit a review article on Lyme disease in California into the <u>Western Journal of Medicine</u>. This journal had previously

requested that his review article be only two paragraphs in length. Some editorial changes have since occurred and he has now been informed that an article of 1500 words or less would be acceptable. Dr. Lane will pursue decreasing the length of his review article for submission to the <u>Western Journal of Medicine</u>. Dr. Lane also reported that his article "Lyme Disease in California" had recently been published in the University of California, Division of Agriculture and Natural Resources publication, PEST NOTES. The article is available on the web at: http://169.237.210.130/PMG/PESTNOTES/pn7485.html.

Dr. Kjemtrup reported that Action Report, a publication of the medical board of California, has in the past accepted one-page alerts from the Department of Health Services (DHS), and would be a good place to publish a "Lyme Disease in California" alert. It was asked how many physicians Action Report would reach; Dr. Morrow noted that there are about 66,000 physicians in California who would receive the alert. Consensus of the Committee was that the Medical Alert was a good place to submit an article for physicians.

Other publications that Dr. Kjemtrup has investigated for submission of Lyme disease articles include <u>California Family Physician</u> and HMO newsletters. Drs. Stricker and Morrow suggested that publications for dermatologists would also be appropriate venues. Since many of these publications require physicians to author the articles, Dr. Kjemtrup said that she would be willing to work with the physicians in the group to get articles submitted. Drs. Stricker and Morrow said they would investigate other Californian medical journals appropriate for publication of articles on Lyme disease in California.

Dr. Kramer stated that Drs. Fritz and Vugia of DHS have already authored an article on "Controversies of Lyme disease" and are currently considering which journal to submit this article. Dr. Lane suggested that the <u>Western Journal of Medicine</u> would probably be the best place to submit the article in terms of wide readership, but noted that it would have to be decreased in length significantly. Drs. Barbour, Morrow, and Stricker and Ms. Hubbard requested copies of the article.

The Committee recommended that Lyme disease in California articles should mention the formation of the LDAC.

The discussion turned to accessibility of physicians to educational material. Dr. Barbour noted that physicians in California would benefit from direct mailings-particularly one that would include graphics of erythema migrans (EM) rashes. He noted that many physicians are simply unaware of what an EM rash looks like. The Committee agreed that this would be a good approach. Dr. Morrow added that the EM rash is not always seen in early Lyme disease. Dr. Morrow also said that he could get some mailing labels from CMA for the mailing efforts if needed.

Dr. Kjemtrup continued her report on efforts to address physician education and noted that she would be giving a presentation in February to a group of physicians at UC Davis entitled "Lyme disease in California: assessing and improving physician awareness." It was suggested by both Ms. Hubbard and Dr. Lane that a questionnaire assessing physician awareness of Lyme disease in California be handed out before the presentation and then collected afterward. It was noted that an assessment of California physician awareness of Lyme disease in California is needed and the venue that Dr. Kjemtrup mentioned would be a good location to test a questionnaire. Such a questionnaire could also be mailed out with the EM photos.

Dr. Morrow wondered how many physician presentations Dr. Kjemtrup was planning to make. Dr. Kjemtrup replied that she would like to do as many as possible and would be grateful if the physicians on the Committee in particular could recommend suitable physician groups for Lyme disease presentations.

Ms. Hubbard mentioned that she would be attending the American Pediatrics Association meeting to be held in Monterey in April. She suggested that it might be a good idea to have an exhibit at that meeting. Dr. Kjemtrup asked Ms. Hubbard to e-mail some information to her about that meeting.

Dr. Kjemtrup reported that the Wildlife Society will be holding a Lyme disease workshop on February 23, 2001, at the Radisson Hotel in Sacramento, California. She will give a presentation entitled "Lyme Disease in California and the Lyme Disease Advisory Committee" and Dr. Curtis Fritz, also of DHS, will give a presentation on the Lyme disease vaccine.

Dr. Kjemtrup then discussed the progress on DHS' Lyme disease brochure. The text of the brochure has been rewritten but still needs editing and will be made available for the Committee to review by the next meeting. She discussed some of the problems with the current brochure, including over-estimation of percentage of Lyme patients showing an EM rash and the need for better graphics. She passed around some black and white photos of ticks that she and other biologists at DHS had worked on as examples for what would be in the brochure. Black and white was used because, in addition to brochures that DHS will produce, the brochure will be reproduced by other agencies and may also be printed off the web. This, in addition to the cost of color production, is why good quality black and white photos are being considered.

As an example of a new brochure with nice graphics, Dr. Murray shared a brochure on Lyme disease prepared by Pfzier and available on their web site.

Dr. Kramer reported that the Mosquito and Vector Control Association of California (MVCAC) has a Lyme disease brochure that has good pictures of EMs.

Discussion ensued about whether to produce DHS' brochure in color or black and white. Ms. Hui was concerned that since black and white brochures are neither eye-catching nor popular, DHS' brochure would be overlooked when placed next to other colorful brochures. It was suggested that it can be produced both ways and the color one posted on the web. A separate web site with more graphics was also suggested. VBDS documents on Lyme disease are currently available on the Disease Investigation and Surveillance Branch web site: http://www.dhs.ca.gov/ps/dcdc/html/publicat.htm. Dr. Kjemtrup noted that the web site was a good idea since it can potentially be more dynamic than a brochure. Whether printed or on the web, however, all material destined for public viewing must go up a chain of approval in DHS before it can be distributed. The Lyme disease brochure was last updated in 1999.

Mr. Parlier suggested that the reporting procedure for Lyme disease cases be included in the brochure.

Dr. Kjemtrup then showed DHS' "Tick Warning Poster," which is posted by state and county personnel in areas where ticks are found. She will be revising this poster using more realistic images and indicating the actual sizes of ticks.

Dr. Lane mentioned that a questionnaire for the public assessing Lyme disease knowledge may also be useful. Dr. Murray said that the California Behavioral Risk Factor Study, a yearly telephone survey financed by the Centers for Disease Control and Prevention and conducted by DHS to assess the prevalence of and trends in health-related behaviors in the adult California population, would be a good place to pose such questions.

Dr. Kramer relayed that this year's survey included two questions on Lyme disease. (She noted that each question in the survey costs \$2,000 to administer.) Approximately 4,000 Californians are surveyed. The study has just recently begun and results are usually released early the following year (2002). The questions on Lyme disease included in the survey were:

Have you ever heard that Lyme disease can affect people in California?

- a. Yes
- b. No
- c. Don't know/Not sure
- d. Refused

Have you found a tick on your body or clothing in the last year?

- a. Yes
- b. No
- c. Don't know/Not sure
- c. Refused

Dr. Kjemtrup pointed out that physicians and the public have access to *California Monthly Communicable Disease Tables* at DHS' Division of Communicable Disease Web site. These tables display monthly disease summaries of reportable diseases, including Lyme disease. Ms. Hubbard said that the small number of reported cases may actually be used to support the argument that there is "no Lyme disease in California." Dr. Kjemtrup said that under-reporting is a chronic problem with most reportable diseases and that she will emphasize the importance of reporting Lyme disease in her physician-oriented talks. The responsibility of evaluating Lyme disease case reports has recently been transferred to Drs. Fritz and Kjemtrup. They have developed and are maintaining a database of all the reported cases, meeting the national surveillance criteria or not. Dr. Morrow noted that this was important since some physicians who had reported Lyme disease in the past had stopped reporting because they felt that too many true cases were discounted.

Finally, Dr. Kjemtrup reported on DHS activities regarding Lyme disease surveillance. Dr. Kramer facilitated the formation of a *Borrelia* Diversity Working group consisting of representatives of institutions involved in the molecular characterization of *Borrelia* organisms. Members include Drs. Kramer, Kjemtrup, Barbour, Lane, Fritz, and Dr. Tom Schwan of the NIH. The impetus behind the formation was Dr. Schwan's report in October of 2000 at the Society of Vector Ecology Conference that at least four to five genomic groups in addition to *Borrelia burgdorferi* and *B. bissettii* have been found in California. The ticks in which the different genospecies were found came from southern California. Whether these different genomic groups cause human disease is unknown. To begin to address the potential for novel genospecies to cause human disease, a collaboration has been set up between DHS and Dr. Lane, who has an NIH-funded grant to isolate *Borrelia* organisms from EM rashes. DHS has agreed to facilitate contact with other physicians in the state who may have patients interested in participating in the study. Issues surrounding the different institutes' requirements on research on human subjects are being worked out.

Other efforts to identify new genospecies of *Borrelia burgdorferi* in California include efforts by VBDS to test ticks, particularly from southern California. Dr. Kjemtrup reported that VBDS has recently developed the capability to conduct fluorescent antibody screening tests for *Borrelia* organisms in ticks. A nonspecific antibody will be used so that *Borrelia* species outside of the *B. bizettii* and *B. burgdorferi* sensu stricto can be identified. Positive samples will be split for culture and molecular characterization by collaborating laboratories.

6. Discuss and prioritize goals and recommendations

The focus of the meeting shifted to the specific goals established at the last meeting. Dr. Kjemtrup pointed out that although the goals suggested in the last meeting were worthwhile, several were beyond the purview of the Committee or DHS. Dr. Kramer suggested that, instead of simply disregarding these goals, the remainder of the

meeting should be spent evaluating and rewording the goals as educational outreach tools or as concrete actions that the Committee can recommend.

Edited goals are listed in the new goal matrix (attached). Discussion surrounding some of the goals is listed below.

Educate Medical Community. 6-12 months.

See goal matrix

Educate Medical Community. 18 months.

See goal matrix

Educate Medical Community. 2-4 years.

See goal matrix

Educate General Public. 6-12 months.

It was noted that the goal "address specific issues such as sexual transmission and breastfeeding" could not be addressed by this Committee or DHS since this is a research, not educational, issue.

In discussing increasing the number of press releases from DHS, Dr. Kramer indicated that DHS distributes a press release regarding tick borne diseases once a year, typically in May. These announcements go up a chain of approval in the Department before they are released. Whether a television or radio station chooses to publicize the announcement is up to the individual station, not DHS. The Committee suggested that public service announcements be made available two or more times a year.

See goal matrix for other changes.

Educate General Public. 18 months – 4 yrs.

See goal matrix

Risk Assessment. 6-12 months.

See goal matrix

Risk Assessment. 18 mon.-2 years.

The former goal "Role of related spirochetes in causing human illness elucidated" was addressed by the addition of "Formation of working group on *Borrelia* diversity" at the 6-month Risk Assessment.

The former goal "Disease tracking through lab reporting" was changed to "initiate efforts to add lab reporting of Lyme disease tests" This was done because the Vector-Borne Disease Section does not have the authority to mandate a disease reportable by laboratories. Also, the "development of in-house testing" was removed because VBDS will not have a laboratory that will test human samples. The former goal "Tissue registry / pathology (hoped for outcome of DHS and Committee work over time)" was removed since this is not a goal that could be addressed by the LDAC or DHS.

Risk Assessment. 3 yrs – 4 yrs.

It was noted that the former goal "Ascertain actual risk by locale (by disease)" was virtually not obtainable since prevalence in tick populations fluctuates on both time and various spatial scales.

Disease Prevention. 12 months.

When addressing the funding issue for Lyme disease, Dr. Barbour asked if the Committee was going to talk to the legislature about funding. Dr. Kramer reported that she would be attending a meeting on Friday to discuss mosquito-borne virus surveillance funding and will try to expand funding to include Lyme disease.

Disease Prevention. 3 yrs – 4 yrs.

See goal matrix

7. Schedule next meeting

Dr. Kjemtrup will be contacting the members to schedule the next meeting.

8. Adjourn

Dr. Lane adjourned the meeting at 3:45 p.m.

Jan. 10, 2001: Goals that the Lyme Disease Advisory Committee Would Like to See DHS Address Goal Area 6 months 12 months 18 months 2 years 3 years 4 years Submit articles to physician Assess physician awareness on LD in Hold periodic tick-borne disease conferences Conduct follow-up assessment on Encourage ongoing physician education: California physician knowledge, journals and newsletters (in California **Educate Medical** -Design educational material for medical develop questionnaire (will awareness on Lyme disease in progress) continue into future months) community (seminars, newsletters, California California (2-3 year goal) **Community** Assess laboratory methods used in Medical Association/California Council of at least 5% of providers California Local Health Officers) recognize, can diagnose and develop questionnaire to address Design direct mailings to physicians of treat LD methods used and the percentage of Lyme disease educational/informational physician and public awareness tests positive material, including myriad of symptoms are comparable, and much that occur greater than at present Develop paper on controversies addressing: Current tests do not rule out Lyme disease Latency and relapse occur Long-term treatment controversies Develop Lyme disease compendium that Develop PSA's (public service Post areas of risk with information Update brochure (in progress) Establish communication announcements) for radio explains DHS's role (may extend to 2 years) about prevention (on-going and in **Educate General** Contact press, initiate informative press Perform a behavioral risk assessment by network and information progress) releases on LD at least twice per year clearinghouse (in progress) incorporating questions on Lyme disease in the Public Provide consultation to and collaborate California Behavioral Risk Factor Study to help Target high risk groups for presentations (on-going) with LD support groups to facilitate develop a public awareness campaign based on Collaborate with local vector public education (on-going) documented needs (in progess) control districts to: coordinate public services develop media contacts. educational materials within their jurisdiction (on-going) Design and implement school education programs in collaboration with local vector Educate School control agencies so that even school children Children know about Lyme disease Encourage tick checks so that they will be conducted routinely by the public in high risk Design educational stickers for the general public and school-age children Form working group on Borrelia Conduct tick surveillance in select Contact local vector control districts Encourage tick studies diversity (done!) regions of California (on-going) and academics to obtain local data on in every county Risk Assessment Provide surveillance data to public as tick abundance and infectivity rates: showing nymphal part of a public education program compile data into report (include map) infectivity rates. and put on web site. Initiate efforts to add Encourage ongoing research of Encourage and facilitate local vector infectivities in reservoir / sentinel laboratory reporting of control districts to conduct nymphal Lyme disease tests animals (on-going) and adult tick surveillance; provide Create new detailed database of reported consultation as needed cases, including all cases whether they fit CDC criteria or not (in progress) Target select physicians to encourage/facilitate their Lyme disease reporting Pursue funding for LD education Enhance public Increase awareness such that legislative knowledge on tick-**Disease Prevention** funding is made available for LD borne diseases and tick research control